

Bardet-Biedl Syndrome UK

Registered Charity No. 1027384 and SCO41839



BBS UK Winter Newsletter 2018



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Foreword

If we have got our timings right, this edition will arrive at the start of the festive season, so pop the kettle on, grab a mince pie and put your feet up as you catch up on the BBS UK news.

Inside this Winter Edition you will find reports from the Birmingham Social Weekend and the Family Activity Weekend, both of which were enormous fun and a great success. Planning is well under way for the highlight of the BBS UK calendar, the Annual Weekend Family Conference, which next year will be held across the weekend of the 26th-28th April, once again at the Hilton Hotel, Northampton. Booking forms were sent out in October and can be found on our website and Facebook page.

Also enclosed are two incredibly inspiring interviews with fantastic role models, Tom Oates and Maria Dowswell, about their achievements in running and Zumba respectively and Richard Zimble has provided a fantastic account of his holiday in Australia with Rachael Foley.

This newsletter is only possible with your support and you will also find inside, easy ways to raise funds for the Charity and different ways of providing support through volunteering. We look forward to hearing from you over the coming weeks and months, but in the meantime, on behalf of everyone at BBS UK, we wish you a happy and peaceful Christmas and New Year.

Sight Village, Birmingham



In July, BBS UK Family Support Officer, Amy Clapp and BBS UK Volunteer, Aneeba Ahmed attended the Sight Village event held at Cranmore Park Conference and Event Centre in Solihull, Birmingham. Aneeba sent us this report:

We didn't have a BBS UK stand this year but Amy and I attended Sight Village to represent and promote BBS UK.

There was new technology and improved equipment which I had the opportunity to try out, including some incredible glasses that can enhance your vision using 'intelligent image interpretation technology'. The cost of these is very high but there are a number of ways that it can be significantly reduced especially if you are a student. There was also the Sonar Smartwatch which was very similar to wearing a Fitbit and is the only smart-band that guides you around obstacles, using sonar or echolocation to detect objects up to 16 feet or 5.5 metres away. Haptic vibration feedback informs how close (or far away) you are to obstacles; the Sonar Band

compliments the white cane, guide dog or low vision.

The rest of the day was spent collecting information for BBS UK and joining in activities. We chatted to England and Wales Blind Golf, Disability Bowls, British Blind Sport and Kathryn Fielding from Goalball UK; Kathryn suggested BBS UK put a team together to play against other charity teams. I joined in with bowls and goal ball.

We listened to a talk about a Safari Holiday that 'Travel Eyes' hosted. It sounded fantastic but rather expensive at £3,400 for a week, although this price does include a personal sighted guide, flights, transfers, breakfast, some lunches/evening meals and all excursions. There are lots of alternatives, at cheaper prices.

I thought the event was very productive, it would be great if a few of us could attend next year to represent BBS UK.



BBS UK Clinics News

The BBS UK Family Support Team have had a very busy few months supporting the specialist clinics and providing support and advocacy services to attending patients and families. New referrals continue to trickle in and the clinics teams have been looking at ways to increase capacity and reduce waiting times. NHS England have agreed to the concept of 'tele-clinics' (consultations by telephone). This will allow those who find travelling to hospital too difficult, or who are in good health, to be able to have a consultation from the comfort of their own home, which in turn will free up appointments for those who need to be seen more regularly. The concept is in development and should make a positive difference to the service once up and running.

The increasing waiting time between appointments is a concern and is exacerbated by missed appointments. At each centre, we only have eight clinic days per year and each missed appointment not only increases waiting times for all but costs the service a great deal of money; a missed appointment at a BBS multi-disciplinary clinic isn't just one missed appointment, it is six or seven missed appointments. In a lot of cases, the clinics team are informed of a cancellation far too late to be able to fill the empty space and in some cases, could have been informed much earlier. We ask that all patients commit to working together with the BBS UK Clinics Support Team to ensure each clinic space is full which will protect and help reduce the waiting times for all.

As a rare disease group we are incredibly lucky to have access to a first class multi-disciplinary service and we regularly come across other rare disease groups who are desperate for a similar service for their patients. This year we have seen two centres, Birmingham Children's Hospital (BCH) and Guy's and St Thomas' Trust (GSTT) move to purpose built Rare Disease Centres, providing excellent facilities for our clinics service.



Waterfall House, the new Rare Disease Centre at Birmingham Children's Hospital opened this summer and is the UK's first rare diseases centre for children. The BBS Birmingham Children's Clinic moved to the new centre on the ground floor of Waterfall House in August and feedback from attending families has been very positive; facilities include a family area, play areas, kitchen, sensory room, 'chillout' room, disabled toilets, braille and induction loop hearing, nine consulting rooms, a research room and a seminar room. Waterfall House is on Whittall Street, down the side of the main hospital building; we look forward to welcoming all our Birmingham Service families to the new centre over the coming months.





We held our first BBS Clinic at Guy's and St Thomas' new Rare Disease Centre in January, as reported in the summer newsletter, however it was officially opened in September by Her Royal Highness, Sophie, Countess of Wessex. Stefan Crocker was invited to meet Her Royal Highness and spoke to her about BBS and the new centre. The BBS UK Support Team were also invited to the opening and enjoyed various presentations and the official unveiling of the plaque.

The BBS UK Support Team also attended a two-day Breaking Down Barriers workshop and thoroughly enjoyed the BBS UK Activity Weekend and Birmingham Social Weekend, reports of which can be found throughout this newsletter. We look forward to catching up with some of you at clinic over the coming months, however if support or advocacy services are needed in the meantime, contact information can be found at the back of the newsletter.



Maria Dowswell: Zumba Instructor

Maria Dowswell achieved the Basic Steps Level 1 Zumba Instructor Award on 15th July 2018, which means she can now teach Zumba classes, which is a fantastic achievement. Maria has started teaching Zumba at WESC Foundation, Specialist Centre for VI and is thoroughly enjoying teaching the classes. Maria is developing and teaching more and more routines as her confidence improves. Maria enjoys Zumba so much that she still attends classes herself, which helps keep her fit and socially active. BBS UK interviewed Maria, to find out a bit more:

What made you start Zumba?

I found out about classes in my local area and decided to give them a try, I thought, 'What have I got to lose?' I wanted to do a social activity that would fit in with my life and I wanted to do some exercise to improve my general fitness; I have been doing Zumba for three and a half years now.

Why do you enjoy Zumba?

I enjoy Zumba because I like the music, the time just goes so quickly when I am in a Zumba class and dancing to the music. I have a group of friends that I see at class so Zumba is part of my social life and keeps me fit. And it's so much FUN, it's a FUN way to exercise.



When did you realise you wanted to become a Zumba instructor?

The classes I attend are great and motivated me to want to become a Zumba instructor. My instructor has given me a lot of confidence and has been a good role model. I decided I wanted to become a Zumba instructor a year

ago but had to wait for the right course to become available in the right area. As soon as the course became available I booked straight onto it.

What motivates you to teach people?

I am motivated when I see others copying me and listening to me and I can see that I am inspiring them to keep going, which in turn keeps me going. If I can make one person feel better after they have attended a class, I have done my job.

How has Zumba helped you?

Zumba has helped my fitness. I look forward to my Zumba class as it's fun and sociable. Since teaching I have grown in confidence and enjoy getting feedback and evaluating what I have taught, which helps me to improve.

What advice would you give to someone wanting to start Zumba or any other exercise class?

Give it a go, what have you got to lose? If you don't enjoy it try something else but give it a go first. Always tell the instructor if you have an injury or that you are visually impaired, so they are aware and can support you and make adaptations if needed; Zumba is inclusive.

What are you hoping to do with your Zumba qualification in the future?

I want to do more Zumba courses, especially the Zumba Kids, so I can teach under 18s. In the future I would like Zumba instructing to be my main job and main source of income. I will continue to attend Zumba classes as well as teach them, as I think it's important to always keep learning.

Birmingham Social Weekend



BBS UK held their third Social Weekend in Birmingham across the 28th to the 30th September and what a fabulous weekend it was. We stayed at the Holiday Inn, near New Street Station and were looked after superbly by the hotel staff. On the Friday night we went to Ask Italian and finished the evening with a quiz in the hotel bar, which included a tactile, 'guess what's inside the sock' round and a music round; great ideas for our next Conference Quiz!

On the Saturday we went to Hollywood Bowl where we had one game followed by lunch. Everyone really enjoyed the bowling and the opportunity to make new friends and catch up with old ones. After lunch we headed off to the Alexandra Theatre to watch Saturday Night Fever. The show was superb and had everyone singing along and at the end, everyone was up dancing; we left the theatre absolutely buzzing!



We had a gala dinner and raffle in the evening followed by cocktail and mocktail making, which went down an absolute storm! We had two bartenders demonstrating and assisting and everyone got to make two or three cocktails or mocktails; it was a fabulous end to a fabulous day.

Sunday morning we enjoyed a cooked breakfast before saying our goodbyes; numbers were exchanged with promises to meet up again. This fantastic weekend would not have been possible without the support of our wonderful volunteers; our heartfelt thanks go to everyone who helped out over the weekend, you are all stars.



If you would like to help out at a future event, please contact Tonia Hymers:

tonia.hymers@bbsuk.org.uk

Breaking Down Barriers

The BBS UK membership and patient group is ethnically diverse and at BBS UK we are keen to ensure that our support services are reaching all aspects of our membership. BBS UK are members of the Sylvia Adams Charitable Trust funded project, Breaking Down Barriers and we have enjoyed working alongside some inspiring individuals to develop our projects and services.

Funding, mentoring and workshops have been provided across a three year period to help patient organisations join together to support families that have an increased risk of having children with genetic conditions within diverse backgrounds and who have difficulty accessing mainstream services. The project has enabled BBS UK to develop a greater understanding of and provide greater support to ethnically diverse families and individuals,



which in turn will facilitate greater access to the specialised BBS Clinics.

Key aims for BBS UK centre around ensuring that our services and activities are inclusive and accessible to all. We ensured that there was a 'reflection and prayer' room available during conference weekend and that food options were appropriate for all cultures, which was

extremely well received. We are in the process of having an information leaflet translated into Urdu and Turkish and another translated into 'Easy Read'.

We recently attended a two day Breaking Down Barriers workshop where we shared our progress with other groups and learned from each other's projects. We are extremely grateful to Jane Young and the Sylvia Adams Trust for funding this invaluable project and

of course to Kerry Leeson-Beevers of Alstrom Syndrome UK for driving the project and being so encouraging and supportive.

We would love to hear from any BBS UK members from minority ethnic communities who would like to get involved with this project. Please contact Tonia, Angela or Amy for more information (contact details can be found on the back page).

Adventure 'Down Under'

Richard Zimble

In June and July of 2018, Richard Zimble and Rachael Foley enjoyed a fabulous trip to Australia to stay with Richard's family. This is Richard's holiday diary:

28th June 2018

Departure Day! We arrived at Manchester Airport and made our way to the assistance office where we were supported with checking in our suitcases and collecting our boarding passes; we were allocated our seats for the journeys from Manchester to Dubai and Dubai to Brisbane.

We were guided back to the assistance office where we said goodbye to our mums and were taken through security by the assistant, Mike. Mike was very professional and made sure all of our belongings were kept together as we went through security.

Mike guided us to get a hot drink and find a seat while we waited to be taken to the plane. When it was time to board, Mike guided us to the door of the plane and the cabin crew helped us to our seats. We were shown how to use the oxygen masks and life jackets, were assisted with the TV and were told to press the call button if we needed anything. For the entire journey the staff looked after us really well; every 20 to 30 minutes they came to check we were ok and to see if we needed help with anything.

At Dubai International Airport we were taken through check in and security by wheelchair as Dubai Airport is massive and it would have taken too long to get to our connecting flight.



At Brisbane International Airport we were assisted off the plane and taken in an electric buggy through customs. We were then guided by the assistant to get our suitcases and taken to where my Dad was waiting for us – we were going to stay with my dad and step-mum in Queensland.

7th July 2018

One of the highlights of our trip - a road trip to Sydney. My dad drove and on the way we stopped off at Byron Bay. We had a walk around and saw the lighthouse before setting off for our motel which was in Yamba; we went out for a lovely Indian.

8th July 2018

We set off for Sydney and drove as far as Coffs Harbour where we stopped for a bite to eat. There is a statue of a big yellow banana made out of fibreglass, which you can walk through. We finally arrived at our destination, a lovely apartment hotel in Pennant Hills about twenty minutes away from Sydney City Centre.

9th July 2018

We went to Parramatta to catch a Ferry Cat to Circular Quay and Dad described all the sights to us, especially Sydney Olympic Park and the Sydney Harbour Bridge. We got to Circular Quay and walked to the Sydney Opera House to book tickets to see singer/songwriter, Regina Spektor. After lunch at a lovely pub we went to an Aboriginal shop to buy some souvenirs to take home. We walked back to the Sydney Opera House and the show was really good. The acoustics in the Opera House were amazing; they have some rings that look like polo mints to help elevate the sound.

10th July 2018

Visit to Taronga Zoo in Sydney. This is a lovely zoo and we saw so many animals such as Asian elephants, giraffes, gorillas, Tasmanian devils, a funnel web spider and koalas. We really enjoyed the zoo and bought some items from the shop to take home.

11th July 2018

We set off back to Queensland stopping off on the way at a lovely cafe in Glen Innes for breakfast. Our stop off destination was a motel in Armidale; we checked in and went out for a lovely Mexican meal. The next day, we set off back for Queensland stopping off at a winery on the way. We stretched our legs, did some wine tasting and bought a bottle each to take home.

21st July 2018

We went to an event called Degustation Day to celebrate Christmas which many people do in Australia in July as their winter months are June, July and August. The table was laid out with little Christmas trees, lights and crackers. The meal consisted of eight courses of small portions. We had an amazing time and it was nice to spend time with everyone, chatting and having a dance.

23rd July 2018

Visit to the Lone Pine Koala Sanctuary where we were able to have our picture taken with a five year old koala called Jervis. We also got to feed and stroke kangaroos, which was amazing as they were so lovely and soft to touch. We saw so many animals including emus, a crocodile, sea turtles, a lace monitor lizard, an inland taipan snake and a cassowary bird. We travelled to the sanctuary on a River Cat and enjoyed a running commentary of interesting

facts. On the way back, I was able to have a go at driving the boat with help and instructions from the captain.

24th July 2018

Lunch at the Yatala Pie Shop followed by rum tasting at the Beenleigh Rum Distillery; we tried all of the different rums and bought some gifts from the shop to take home. In the evening we went to a show called The Outback Spectacular. This was an amazing show with live horses, quad bikes and a car and a utility truck.

25th July 2018

Picnic on the beach at a lovely place in Brisbane called Paradise Point; the sand was lovely and soft and it was nice sitting on the beach sunning ourselves and just listening to the waves as they went in and out. We saw lots of little blue swimmer crabs at the water's edge and when they felt under threat they buried themselves in the sand.

26th July 2018

Visit to an outlet shopping centre called Harbour Town where we shopped till we dropped, getting last bits of souvenirs and gifts to take home.

27th July 2018: Final Day

Lunch at the top of Tamborine Mountain. On good days people will hang-glide off the top. My dad described all of the wonderful views from the mountain's edge. It was then time to head back to finish packing and depart for Brisbane International Airport.

My dad and step-mum drove us back to Brisbane International Airport and helped us to check in. A member of staff made sure that assistance was booked for all the airports, that all the meals were correct for the journey home and that we were given seats together on all the planes.

We were looked after just as well on the way home as we were on the way there by all the cabin crew and airport staff, nothing was too much trouble. When we arrived back in the UK, Rachael's parents were there to meet us and take us back to Stockport.

Directors Needed for BBS UK Clinics Ltd

BBS UK Clinics Ltd was set up by BBS UK to manage the contract it holds with NHS England to provide support and facilitation services to the specialised clinics service. The day to day management of the Company is the responsibility of the Service Manager, Tonia Hymers. The Board of Directors meets once a year, usually in November, for the Company's Annual General Meeting. The developments and issues of the previous year are discussed and future planning is undertaken. Unless any significant issues arise, all other management and decision making is undertaken via telephone calls and by email.

The role of Director is a voluntary one (non-remunerative) however all reasonable expenses are paid. There are two vacancies

on the Board and we would like to invite interested parties to apply. In particular we are interested in individuals with good communication skills, the ability and willingness to attend meetings in London and any of the following:

- ✓ Relevant business knowledge/experience
- ✓ Finance, human resources or legal knowledge/experience
- ✓ Knowledge/experience of the NHS and/or contract management

If you think you have the skills and experience needed to join the BBS UK Clinics Ltd Board of Directors, please email tonia.hymers@bbsuk.org.uk for an application form.

Tie and Tiara Fund Raiser

On 8th June 2018 Rachael Foley, Liam Dempsey and Richard Zimble hosted a Tie and Tiara fundraising night at The Manchester Hall.

The event was to raise money for BBS UK and Greater Manchester VI Bees. The event was well supported and included a DJ and raffle with a large array of prizes. The event, through kind donations, raffle and entrance fees raised a grand total of £700. This was split equally between BBS UK and Greater Manchester VI Bees, which meant each great cause received £350.

The event was hailed a great success and we would like to thank everybody for attending and for all their kind donations.



We would also like to thank all of the companies and organisations that kindly donated raffle prizes.

BBS UK Events Page



BBS UK Weekend Family Conference

26th – 28th April 2019

Planning is well underway for the biggest event in the BBS UK calendar, the Weekend Family Conference! The programme is yet to be finalised and confirmed, but will include:

- ✓ Updates on the latest research and developments in BBS
- ✓ Inspiring personal perspectives
- ✓ Interactive workshops
- ✓ Children and young people's outing to Drayton Manor
- ✓ Family Quiz and Raffle, crafts and activities and so much more...

Booking forms can be downloaded from the BBS UK website, www.bbsuk.org.uk or email info@bbsuk.org.uk

Space is filling up fast, so we advise delegates to book as soon as possible to avoid disappointment.

We look forward to seeing you there.



Family Activity Weekend

6th-8th July 2019

We are in the early stages of planning the next BBS UK Activity Weekend which will be held in July 2019 at the fabulous Whitemoor Lakes Activity Centre, Lichfield. A report about the 2018 activity weekend at Whitemoor Lakes can be read elsewhere in this newsletter and further information and booking forms will be available over the coming months.

If you would like to be added to the BBS UK Children's Activities and Events Mailing List, email info@bbsuk.org.uk.

Fundraising Round-up

We are truly grateful to everyone who fundraises for BBS UK. All your fundraising is appreciated because the more we raise, the more we can do. We would love to share your inspirational stories so if you would like a mention in our newsletter or on our Facebook page, please get in touch with dianne.hand@bbsuk.org.uk.

As President of Lockwood Bowling Club, Bob Prince kindly chose BBS UK as the charity he was going to support this year because his Granddaughter, Holly, has BBS. Joining Bob and Holly in the photo is Holly's sister, Lilly, and Sonia and Joy. Sonia and Joy are also members of Lockwood Bowling Club and they have been wonderful in supporting Bob by raising money for BBS UK at car boot sales. Along with Bob, and Holly's dad, David, they were up at 5am to get the best pitch opposite the mobile tea van and Bob would be armed with a big bag of doughnuts to keep their energy up!

On Bob's President's Day, the club held a large raffle with lots of items donated, which raised a considerable amount of money. There have also been collection boxes within the club house which members have donated generously to throughout the year.

Thank you, Bob, and everyone at Lockwood Bowling Club for raising the fantastic amount of £1570.47 (with more to come!)

We would like to publicise anything you are doing to raise money and give you encouragement in any way we can. Some of you are already in training for events where you hope to raise lots of money for BBS UK.

With 40th birthday celebrations looming in April 2019 for Ashley Wilkie and Emma Mitchell, they are both excited to be taking on the challenge of the Virgin London Marathon when they will proudly fly the flag for BBS UK! They will be supported by their good friends Karen Stewart and Catriona Townsend who have all been committed to fundraising in support of Ashley's daughter, Caitlin, throughout the year. Keep an eye on



our Facebook page for details of how you can support Ashley and Emma as they continue to passionately raise funds for BBS UK.

Another of our fundraisers is Andrea Howlett who will be taking on the challenge of the Manchester Marathon in April 2019. Andrea will be running in memory of her mum, Jean Wilkinson, who was a supporter of BBS UK. You can support Andrea on her fundraising page at justgiving.com/fundraising/andrea-howlett.

BBS UK is a small but national charity, supporting over 500 people with BBS and their families and carers and relies solely on fundraising, donations and grants to fund its work. If you have been inspired to raise funds for BBS UK, below are some simple ways you can help.

BBS UK is registered with easyfundraising which means you can help support BBS UK simply by shopping online with over 3,300 retailers including Amazon, Argos, Marks and Spencer, John Lewis and eBay. Every time you shop, you'll raise a free donation for BBS UK at no extra cost to yourself, it's that easy! To register visit www.easyfundraising.org.uk/causes/bbsuk/.

BBS UK is also registered with Amazon Smile. Follow the link to sign in to your Amazon account via Amazon Smile and Amazon will make a 0.5% donation of the net purchase

price of eligible purchases to BBS UK. Amazon Smile is the same Amazon you know. Same products, same prices, same service. Go to www.smile.amazon.co.uk and support BBS UK the easy way.

We wish all our supporters happy fundraising and look forward to hearing about all the different ways you have been supporting BBS UK over the coming weeks and months; our heartfelt thanks to you all.

BBS UK Trustee Spotlight

Volunteering as a Trustee for BBS UK is an honour and we all work hard behind the scenes to manage the day to day running of the charity, as well as supporting our members in any way we can. We thought it would be a good idea to let you know who we are and why we are involved. We would like to introduce you to four of us in this newsletter.

Stefan Crocker

Stefan has BBS and has been a Trustee since 2015, and vice-chairman since 2017. He writes,

“Being a trustee is very rewarding, primarily as I have input in making decisions on behalf of BBS adults when it comes to issues such as conference planning and other social events. Another role I am developing is as an ‘Adults Contact’. I am keen to encourage adults living with BBS to make the most of life, by sharing experiences and practical tips. Where possible this is done by meetings in person, and by being in regular contact with BBS members, I can give assurance that any important issues will be reported back to the Board. My admin, language and networking skills have developed whilst being a Trustee and I am now more confident communicating with professionals, parents and adult patients alike. I have also been utilising my second language skills by networking with the German BBS group. Most importantly I have made new friends and have enjoyed getting to know people in more depth”.



Laura Dowswell

Laura is married to ‘the ever patient and laid back’ Nick and together they have two grown up children, Maria and Greg. They live by the sea at The Witterings on the south coast and enjoy the beach life all year round. Laura and her family became involved with the charity after Maria was diagnosed with BBS at age 14 and they attended their first conference ten years ago. Laura says they were amazed at the amount of support and information they received and the lifelong friends they made. As a family they were determined to ‘give something back’. Laura has worked in charity finance roles for over ten years and it seemed ideal to join the Board of Trustees and become Treasurer to use her financial experience to support the work of the Charity. Laura writes, “I enjoy being a Trustee and helping to shape the Charity’s future and ensure its long term safety and sustainability”. The family have supported several fundraising events and ventures for BBS UK.



Christian Bolton-Edenborough

Christian is from Potters Bar, Hertfordshire. He was diagnosed with BBS in early 2015 at the age of 20 whilst studying for an LLB Law degree in North Wales. He graduated in 2015 achieving a 2.1 and then a Distinction



in a Law Masters Degree in 2016. Christian is currently studying the Legal Practice Course at BPP University London and aims to become a Solicitor. He competes regularly in the Lawn Tennis Association Visually Impaired Tennis Championships. Christian became a Trustee for BBS UK in April 2018 and his aim is to enhance the Charity's support network, increasing the opportunities that BBS adults and children can participate in. As a representative of the Charity, he endeavours to link up with various visual impaired sporting organisations to set up relationships that will increase sporting opportunities for those living with BBS. Christian wants to help instil confidence in other BBS members to give them the belief that as long as they learn to adapt to their respective limitations then they can achieve anything.

Rachael Foley

Rachael is 36 and lives in Stockport. She was diagnosed with RP in 1996 and BBS in 2012. Rachael studied Leisure and Tourism and worked in a travel agents for a year before moving on to work for Stockport

Council, organising conferences, campaigns and social media.

Rachael is enthusiastically involved with blind football, goal ball and sound tennis. Rachael has gained a Level 1 Tennis Association

Coaching Certificate and is a committee member of Manchester Blind Football Club. Rachael is also Vice-Chair of Greater Manchester VI Bees, a voluntary community group for blind and visually impaired people; Rachael helped to set up and administers their Facebook page, and plans and organises social and sports events.

Rachael became a Trustee because she felt her networking skills and contacts would prove useful in raising awareness of BBS UK and the service it offers and that as a female with BBS she brings a different perspective to the Board.



Healthy Lunch Box Ideas

Now that we are well into the new school year I thought it might be a great time to focus on packed lunches. Did you know studies have shown that most school packed lunches aren't as healthy as school meals? Surprised? Meals in most schools have to comply with a set of standards but the majority of schools allow anything except nuts in a packed lunch. You might remember the sensational headlines back in 2006 when the first study looking at packed lunches in schools was published, an example being '99% junk in kids' packed lunches'. Ten years later and alarmingly, only small improvements were found; more than half of the lunches still contained too many sweet snacks and less than a fifth contained a vegetable.

Have a look at your lunch box – if most of the foods are in packets it is probably time to try

out some new ideas. If you think your lunch box could be improved read on for some ideas to try.

Firstly, choose a starchy carbohydrate food e.g. bread, rice, pasta, couscous or potatoes. Starchy foods provide a variety of important nutrients in our diets, such as B vitamins and they help keep our energy levels up throughout the day too. If you use the plate method to keep your portions in check remember that a quarter of your lunch box should be filled with a starchy carbohydrate food.

- ✓ To make sandwiches more interesting try using a variety of different breads e.g. pitta, multigrain, seeded wraps, bagels, rolls or sandwich pockets. If you can, choose higher fibre varieties e.g. wholemeal pitta or bread. Mixing

- ✓ white and wholemeal bread to make a checkerboard sandwich or 50:50 breads can be a winner for children!
- ✓ If bread is a food that you regularly find disappearing from your kitchen – try keeping it in the freezer so you only take out what you need for the day.
- ✓ Cook extra pasta, couscous, rice or potatoes to use in your packed lunch the next day.

Next, it's time to think about a protein rich food to put in your sandwich or mix with your leftovers. Protein rich foods include beans, pulses, fish, eggs, meat and cheese. Try to choose just one protein food and then add plenty of vegetables or salad.

- ✓ Choose reduced or half fat grated cheese – a little grated cheese can go a very long way!
- ✓ Choose tinned fish such as tuna in water or brine rather than oil. If you mix this with a little reduced fat mayonnaise you won't need to use a spread on your bread.
- ✓ Choose lean, thinly sliced meats
- ✓ Try to prepare your own egg, prawn or tuna mayonnaise filling so you can choose exactly how much lower fat mayonnaise to use
- ✓ Try low fat cheese spreads or cottage cheese for a change
- ✓ Try something different e.g. a couple of falafels and serve this with pitta bread pieces, a selection of vegetables and a portion of hummus to dip everything in

Now it's time to think about adding a vegetable or two. If you've only added a few slices of cucumber or tomato in your sandwich, then you definitely need to try adding extra, so you can be well on your way to hitting the '5-a-day' target. Vegetables contain both a high water and high fibre content which can help us to feel fuller for longer. Most vegetables have a very low calorie content, so you can eat larger portions without worrying. Just remember to

watch your intake of olives. (Fruit-wise watch your intake of avocados too).

It may surprise you how few calories there are in a portion of vegetables – why don't you guess the amount in the portions below:

How many calories do you think there are in 2 sticks of celery?

How about 4 cherry tomatoes?

How about a handful of iceberg lettuce?

The answers are 6 kcals in 2 sticks of celery, 18 kcals in 4 cherry tomatoes and 3 kcals in a handful of lettuce.

Try including a selection of vegetables cut into age-appropriate pieces e.g. raw carrot, cucumber, cherry tomatoes or celery sticks. A low fat dip could be included too – salsa is a great choice.

Now it's time to add some fruit. We all know we should be eating at least five portions of fruit and vegetables every day – but did you know that most of us aren't anywhere near reaching this target? Data from the latest National Diet and Nutrition Survey showed that only just over 30% of adults and 8% of teenagers are actually achieving this goal. I think confusion over what a portion actually is could be contributing towards this. For adults a portion is 80g of fruit or vegetable, don't worry you don't need to get your weighing scales out! For medium-sized fruits a portion is simply one piece of fruit e.g. an apple, banana, pear or orange. For smaller fruits the portion sizes may surprise you and be much larger than you thought, examples include 2 kiwis, 7 strawberries or 3 apricots. I am often asked what size a child's portion should be – a simple rule is as much as they can hold in their hand. Teenagers should aim to eat adult sized portions. Try to add at least one portion to the lunch box but remember it isn't necessarily just one piece of fruit.

Fruit for children needs to be easy to eat. Did you hear in the news the clever way to include an apple in a lunch box? Apparently, if you core and slice an apple into wedges and reassemble with an elastic band the apple is still perfect to eat at lunch time! Children may also prefer ready peeled

orange segments. A selection of different coloured fruits can be more appetising too so try making a fresh fruit kebab or fruit salad (without added juice).

Next, it's time to consider if you need to add a yoghurt? If you have already included a calcium rich food e.g. cheese or tinned sardines; then you don't need to. If not, add a small pot or tube of low fat or diet yoghurt, fromage frais or rice pudding. If you are following a milk free diet, look out for calcium enriched alternatives based on your usual milk substitute such as oat or soya.

Don't forget to put in a drink which ideally should be water. Research has shown that we typically do not alter our food intake when we have a higher energy drink. By changing from sugary soft/fizzy drinks to water or sugar free options, we can cut our energy intake without altering what we are eating!

Now have a look at your lunch box, it should be looking pretty full by now. However, if you are worried that it doesn't look full enough, then add a little something else, healthier choices include:

- ✓ a slice of fruit loaf or homemade banana bread
- ✓ a packet of puffed potato style or corn based savoury snacks e.g. Quavers, PomBears, Skips or supermarket own brand

- ✓ plain popcorn (please note this is not suitable for children under 5 years of age due to choking risk)
- ✓ sugar-free jelly pot
- ✓ a plain biscuit e.g. digestive or rich tea
- ✓ a small box of raisins

If this suggested lunch box appears to be a long way from your or your child's usual packed lunch, then start by thinking about one small change that you could make e.g. adding a vegetable or stopping a sugary drink. It's much better to start small than try everything at once and struggle to keep it up for more than a day or two. A new habit takes a couple of weeks to establish so you could try making a change at the beginning of every month until you're happy with your healthy lunch box.

Feeling inspired but want more support to make dietary changes? If you are a parent of a child attending the BBS clinics contact your dietitian or other member of your clinic team. If you are an adult, your family doctor or practice nurse will be able to help you to find support where you live.

Sarah Flack
Principal Dietitian
Great Ormond Street Hospital
September, 2018

Running For My Life: Tom Oates

Tom Oates gave an inspiring presentation/interview about his Park Run journey at a local 'Tapas and Tales' evening in Ripon in October 2018. Tom is 21 and has Bardet-Biedl Syndrome; he is registered blind and was diagnosed with autism when he was 17. Tom has kindly given permission to include the presentation/interview in this newsletter, which began with an outline of the awards Tom has received to date for fundraising and volunteering:

- ✓ The Stray FM Local Hero Award in 2012 for raising £3000 with a 225 mile tandem cycle ride
- ✓ The Tim Driffield award at St Aidan's High School in 2014 for Courage and Endeavour
- ✓ The Henshaws Fundraiser of the Year Award in 2016 for raising £3000 towards a piece of specialist equipment for the Henshaws gym
- ✓ The Harrogate and District Oscar Award



- ✓ in 2017 for Best Local Volunteer for volunteering at Ripon hospital, Ripon museum, Ripon Cathedral and Fountains Abbey

Parkrun is a collection of five-kilometre running events that take place every Saturday morning in twenty countries across five continents. Starting in 2004, there are now over 550 parkruns in the UK alone with about 130,000 runners taking part each week. Read on to find out about Tom's parkrun journey – you may be inspired to find a parkrun or exercise class near you!

Why did you want to do the parkrun?

When I was at St Aidan's [Secondary School] I kept fit by doing PE classes but after I left I found it hard to keep my weight under control. Having BBS makes me bigger than I like and I wanted to lose weight, so my mum suggested that I try to do a parkrun. Also, I wanted to be fit to help with my self-confidence; I didn't want people saying that I was an unfit, lazy teenager. My mum and dad have always set a good example and they do lots of sporting activities so I wanted to be able to join them.

What have been the obstacles?

Mainly this has been my eyesight, because I am registered blind. I have no peripheral vision and light and shade confuse me. I have no spatial awareness, which means that I find it difficult to judge where other things and people are and how to avoid them. I always need a sighted guide next to me, we have to work together and understand each other. I need to wear a high visibility vest so other runners know not to come between me and my guide. I find the start very difficult and don't like all the people as it makes it hard to get into a rhythm. I have fallen over about three times, once over the dog, once over my friend's



shoes and once on a wooden bridge. But you just have to get up and crack on.

So you started the parkrun in 2014 when you were 17?

Yes, in 2014, I began doing the Fountains Abbey parkrun on a Saturday morning. Because of my vision and lack of spatial awareness, I needed support and would like to thank my mum and dad for all of the help that they have given. There have been other helpers as well; Pam supported me a great deal at first, but now she cannot keep up! At first I was very slow and couldn't manage to do both loops of the run route. I had to begin practicing by walking slowly at the back. I did my first official full parkrun in January 2015 in a time of about 43 minutes and was not too far from the back. I progressed well through 2015 and 2016 and by January 2017 was finishing in 34 minutes. But it was hard to improve after that.

And now I believe that you are regularly finishing in less than 30 minutes?

Yes, I am determined and want to keep improving, so I make sure that I build my strength and running skills. I met Stuart, my personal trainer, in 2017 at Ripon Community Link. He has been amazing and patient and very encouraging with me. I run with him every week for an hour. He coaches me and advises on diet. We monitor my body composition every couple of months – body fat, etc., to keep on track. I also do strengthening and conditioning at the gym with Ben, which helps my running. I first beat 30 minutes on my 100th parkrun.

How many parkruns have you done now Tom? And I expect that you get a lot of encouragement from your Mum and Dad?

I have now completed 128 parkruns, mainly at Fountains Abbey, but I've also done parkruns in Penrith, Brighton, Perth and Lanhydrock. Mum and

Dad also run with me and take it in turns to support me; Dad is much better than Mum. Encouragement? If I fall over it's just 'Get Up Tom', or 'Come on Tom we need to finish' – even if I am bleeding or have torn my trousers! They don't cut me any slack at all...

What is next? I understand that you have won even more awards?

I have done a few 10ks and am now aiming for a 10 mile race. I completed a duathlon with my mum and dad earlier this year. We run together, then I cycle on the tandem with

my Dad and then we all run together again. I love it! I was awarded The Gambaru Adversity Award (2015) for overcoming adversity through sport. Gambaru is Japanese for 'Never Give Up'. I ran the Melmerby 10k in 2016 and won the The Melmerby 10k award for Special Achievement.

Tom, do you have a message for the audience?

Yes – it is that if I can achieve this, so can anyone. You just have to keep going. Gambaru - Never give up!!

Useful Resources

- **Family Fund:** Family Fund is a registered UK charity which provides grants for low-income families, raising children aged 17 and under. It can help with essential items such as washing machines, fridges and clothing but can also consider grants for sensory toys, computers and much needed family breaks together: www.familyfund.org.uk
- **VICTA:** Visually Impaired Children Taking Action (VICTA) supports children and young people who are blind or partially sighted and their families across the UK. If you are visually impaired and under the age of 29, or are the parent of a visually impaired child or young person then VICTA can help. VICTA also have an extensive events and activities programme: www.victa.org.uk
- **LOOK UK:** LOOK UK supports young people up to the age of 29 and their families living with a vision impairment: www.look-uk.org
- **PHAB:** PHAB's mission is to inspire and support children, young people and adults with and without disabilities to make more of life together - breaking down community barriers, reducing social isolation, and creating opportunities for disabled people to enjoy the same activities and challenges as, and alongside, those without a disability: www.phab.org.uk
- **THE MAYPOLE PROJECT:** The Maypole Project provides a lifeline of support for children with complex and life threatening illnesses and their whole family. They provide a range of support to parents from diagnosis through treatment and beyond and provide emotional support to the whole family including siblings and grandparents. Tel: 01689 889 889 helpline@themaypoleproject.co.uk
- **Art Through Touch:** Art Through Touch is an inclusive organisation which provides and promotes access to art for people with a visual impairment. Activities include workshops, seminars, monthly art talks, a monthly newsletter and gallery visits: www.art-through-touch.org.uk.
- **Metro Blind Sport:** Metro is a London-based charity; their aim is to open doors to sport for all vision impaired people, regardless of age or sporting ability. They have sessions throughout the year for archery, athletics, bowls, cricket, cycling, football, goalball, rambling, sailing, skiing, swimming and tennis: www.metroblindsport.org

- **British Blind Sport:** The work of British Blind Sport enables blind and partially sighted people to have the same opportunities as sighted people to access and enjoy sport and recreational activities in the UK: www.britishblindsport.org.uk
- **Mencap:** Mencap's aim is to improve the lives of people with a learning disability and their families now, and fight alongside them for a better future. They are part of a network of over 400 local groups reaching out to people across England, Northern Ireland and Wales: www.mencap.org.uk
- **SOS!SEN:** SOS!SEN offers free friendly, independent and confidential support for parents and carers of children with Special Educational Needs. Helpline: 020 8538 3731 (term time only)
- **Ipssea:** Independent Parental Special Education Advice: www.ipsea.org.uk
- **Coram Children's Legal Centre:** Coram Children's Legal Centre provides free legal information, advice and representation to children, young people, their families, carers and professionals, as well as training and consultancy on child law and children's rights: www.childrenslegalcentre.com
- **Through Scarlett's Eyes:** Through Scarlett's Eyes is dedicated to supporting parents and families of visually impaired children: www.throughscarlettseyes.com
- **Disability Grants:** A directory of grants that are available to those living with a disability: www.disability-grants.org
- **Turn2us:** Turn2us is a national charity that helps people in financial hardship to gain access to welfare benefits, charitable grants and support services: www.turn2us.org.uk
- **Natspec:** Natspec is the membership association for organisations which offer specialist further education and training for students with learning difficulties and/or disabilities. The website enables users to search for specialist provision by location and expertise: www.natspec.org.uk
- **CEA CARD:** A national card scheme developed for UK cinemas by the UK Cinema Association (UKCA). The Card enables a disabled cinema guest to receive a complimentary ticket for someone to go with them when they visit a participating cinema: www.ceacard.co.uk
- **ACCESS CARD:** The Access Card is printed with symbols to show your disability and to highlight the barriers you face and the reasonable adjustments you might need, so you don't need to keep explaining. The card costs £15 for three years: www.accesscard.org.uk
- **MAX CARD:** A discount card for foster families and families of children with additional needs. Families simply show their Max card upon entry to a venue in order to obtain free or discounted admission. Email hello@mymaxcard.co.uk or phone 01133 947 951 or see your Local Offer.
- **Dial a Ride:** Transport for London's free door-to-door service for those with permanent or long-term disabilities: www.tfl.gov.uk/modes/dial-a-ride/
- **Ring and Ride:** Ring and Ride is a door-to-door service for those living in the urban areas of the West Midlands who struggle to use conventional transport: www.ringandride.org



Volunteering

Volunteering can benefit the volunteer as much as the cause they choose to help and dedicating your time as a volunteer can help you make new friends, boost your social skills, learn new skills and use and enhance skills you already have.

People choose to volunteer for various reasons. For some it offers the chance to give something back to the community or make a difference to the people around them. For others it provides an opportunity to develop new skills or build on existing experience and knowledge. Regardless of the motivation, what unites them all is that they find it both challenging and rewarding.

Everyone has different skills which are suited to different volunteering opportunities. It is important that an individual is 'matched' to the right volunteering position to enable them to support their chosen organisation and so they benefit from the volunteering experience. BBS UK has a number of volunteers that help the charity; all of these volunteers have been given the opportunity to work with us to ensure their volunteering opportunity suits their needs.

BBS UK would like to take this opportunity to say a huge THANK YOU to everyone who supports BBS UK, your volunteering is greatly appreciated and makes a big difference to the work we are able to do.

BBS UK are always looking for new volunteers and volunteering opportunities. If you feel you would like to volunteer for the charity please contact us and we will work with you to see what volunteering opportunities are available. Volunteering doesn't have to be weekly or at a set time and day, it could be at an event, promoting BBS UK, or at the conference helping support the BBS UK staff team and delegates. BBS UK staff will support you through your volunteering journey and ensure that you are confident and happy in the volunteering position.

We have identified some of the volunteering roles BBS UK currently has, this list is not exhaustive so please contact us with your ideas:

- Why not become a 'Weekend buddy' helping to support visually impaired delegates at the BBS UK Conference?
- Get fundraising on the Conference Weekend tombola and merchandise stall, a great way to meet new people and raise vital funds.
- Sighted guides are required for the Conference Weekend trip to Drayton Manor, to ensure everyone has a fun and safe time.
- BBS UK attends events all around the country, promoting BBS UK and often requires sighted guides to support visually impaired delegates attending these events.
- In your local community why not arrange a 'bag pack' or collection at your local supermarket or ask the local shop if they will have a BBS UK collection tin. This not only raises money but awareness of BBS UK too.
- Write a newsletter article for us, tell us about your experiences, what you have been doing.
- Are you a grammar whiz? Can you proof read and/or edit documents? We have a range of documents that need proof reading and editing, from newsletters to reports.
- Social media volunteers are needed to update Facebook and Twitter.
- Trustees are vital to enable the charity to continue; in particular, we need volunteers with finance, human resources and governance experience.
- Fundraisers help raise vital funds; you could sit in a bath of beans, hold a sponsored silence or jump out of a plane - the opportunities are endless!

Everyone has skills in different areas so please do contact us to see how we could optimise those skills to enable you to become a volunteer for BBS UK.

For more information about volunteering for BBS UK contact: tonia.hymers@bbsuk.org.uk



FRIENDS of BBS UK

Regular readers and those involved in the charitable sector will know that raising funds and applying for grants can be very unpredictable and a charity's successful steady growth can falter in leaner times.

At BBS UK, we rely solely on fundraising, donations and grants and income determines whether there will be a conference in a particular year or how many newsletters will be produced. Producing or re-writing leaflets can be particularly costly and again relies on the charity being in a strong financial position.

The financial stability of our small charity relies on *regular* donations and we are often asked why we don't charge for membership. This would indeed provide that much needed regular income, however it has always been our policy that membership is entirely free.

Several years ago, we set up 'Friends' of BBS UK, a fundraising initiative, giving those members who wished to regularly support the charity, the means to do so and we have slowly built up a strong, loyal band of 'Friends'.

You can become a 'Friend' of BBS UK in the following ways:

- ✓ You can take a collection box and collect for the charity, or organise a fundraising event
- ✓ Complete a regular payment form and make monthly donations to the charity from as little as £1 per month
- ✓ Or you can combine both of the above.

It really is so easy to become a 'Friend' of BBS UK; simply complete the form enclosed with this newsletter and return it to us at the address below and we will do the rest.

If you feel you would like to become a 'Friend', but would like more information, please email finance@bbsuk.org.uk for further information.

Gift Aid forms should be sent to:

BBS UK
1 Blackthorn Avenue
Southborough
Tunbridge Wells
Kent TN4 9YA



FRIENDS of BBS UK

Name:

Address:

.....

.....

.....

Post Code:

Tel No:

I would like to become a Friend of BBS UK:

I have completed the Standing Order form overleaf Tick

Please send me a collection box

I wish to organise a fundraising event and would like a Fundraising pack

Gift Aid Declaration

The Government allows charities to reclaim tax through the Gift Aid scheme at no extra cost to you. At the standard rate of income tax, your gift is worth 20% more to us if you allow BBS UK to claim Gift Aid. Please tick the box below and help us to do more with your donation.

I would like the BBS UK to reclaim the tax on any donation I make. I have paid an amount of UK income tax or capital gains tax equal to any tax claimed.

Thank You



FRIENDS
of BBS UK

Standing Order Form

I would like to become a 'Friend' of BBS UK and make the following regular payment:

Please pay the sum of £

Amount in words:

To: Bardet-Biedl Syndrome UK 'Friends Acc'
Account No: 70901059 Sort Code: 20-88-13

With effect from: (Date)

And **monthly** thereafter.

Please complete the following in **block capitals**:

Name:

Address:

Postcode:

Name of Bank:

Address of Bank:

Postcode:

Account No:

Sort Code:

Reference:

Signed:

Date:

Please complete and return to:

BBS UK
1 Blackthorn Avenue
Southborough, Tunbridge Wells
Kent, TN4 9YA

BBS UK Activity Weekend at Whitemoor Lakes

BBS UK held its third Activity Weekend in June 2018, at Whitemoor Lakes Activity Centre, Lichfield. Once again the weather was on our side with beautiful sunshine from start to finish. Whitemoor Lakes is a stunning purpose built activity centre and we were fortunate to have the entire centre to ourselves.

Friday evening, we set up a table of craft activities followed by a movie night, complete with popcorn. We also had a huge bouncy castle to ourselves for the whole weekend which went down a storm with children and adults alike. The bouncy castle was in a huge sports hall with access to a basketball court too. The craft and movie room had tables outside overlooking the lake, which meant the adults could enjoy sitting outside and chatting, whilst keeping an eye on their children/young people.

Saturday morning started off with a cooked breakfast before the first of the day's activities on the lake. The group split up with guests enjoying sailing, canoeing or raft building. The under 8s weren't able to join in the main activities and followed their own programme



which started off with 'Bottle Boat' building and floating. The sailing and canoeing looked so peaceful – less so the raft building which inevitably ended up with everyone very wet! Angela Scudder and Amy Clapp, BBS UK Support Officers were the worst culprits and made sure everyone was as wet as they were!



After break, we set off for the next round of activities which was archery or high ropes – the high ropes were extremely high. The under 8 group had their own mini archery set and also enjoyed having the bouncy castle to themselves without the bigger ones getting in the way! Lunch was followed by the last activity of the day, abseiling and zip wire or fencing. In between all the activities we also enjoyed the bouncy castle and craft activities. Saturday evening we wandered down to the lakeside campfire where we were entertained by the Whitemoor Lakes activity team. They took us on an interactive storytelling



adventure which was great fun. We also toasted marshmallows and watched a family of swans head off to bed while the sun set – a magical end to a magical day.



Sunday morning and another cooked breakfast was followed by the last activity of the weekend, the assault course.



This was a tough challenge and everyone excelled themselves, working together and encouraging each other across the course. The little ones had their own treasure hunt to follow. Little did we know that there was going to be one last surprise to finish off our weekend, a world record breaking attempt to build the largest wearable balloon animal. We had some time to fill before lunch and the entertainer called us in to the room and gave a free party presentation with a balloon creation for each; we are going to struggle to top that next year. After a lovely lunch, everyone said their reluctant goodbyes and headed home. We really cannot wait to go again and have booked the centre for the weekend of 5th-7th July 2019; booking forms will go out in the New Year.



Contact Details

BBS UK General Contact

Family Support Officer:

London Service

Angela Scudder

Mon-Fri: 9am-3pm

angela.scudder@bbsuk.org.uk

07591 206788

BBS Clinics Service Manager

Tonia Hymers

Mon-Thurs: 9am-5pm

07591 206680

tonia.hymers@bbsuk.org.uk

info@bbsuk.org.uk

New Families Contact

Claire Anstee

Mon-Fri: After 5pm

01604 492916

claire.anstee@bbsuk.org.uk

BBS UK General Contact

Family Support Officer:

Birmingham Service

Amy Clapp

Mon/Tues/Thurs/Fri: 9am-3pm

Wed: 12pm-6pm

amy.clapp@bbsuk.org.uk

07591 206787

Fundraising Support

fundraising@bbsuk.org.uk

dianne.hand@bbsuk.org.uk

BBS Adults Focus Group

richard.zimbler@bbsuk.org.uk

Friends of BBS UK

finance@bbsuk.org.uk

info@bbsuk.org.uk



www.bbsuk.org.uk